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# GENINFO

Newsletter on the Ethical, Legal and Social  
Issues in Human Genetics

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July-August 2009



CENTRE OF GENOMICS AND POLICY  
CENTRE DE GÉNOMIQUE ET POLITIQUES

Dear Readers,

We are proud to announce that, as of June, our team has moved and will now be called the Centre of Genomics and Policy (CGP). Our Centre is affiliated with McGill University's Faculty of Medicine, Department of Human Genetics. Because of our move, please note that the HumGen website has the following address: [www.humgen.org](http://www.humgen.org). Also note that this change will not affect the content of the website. We will continue to provide you with the most up-to-date information regarding policies or legislation in the field of human genetics research. We are excited about this opportunity and look forward to the many new projects this will hold for us!

Our team has moved and will now be called the Centre of Genomics and Policy (CGP). Our

Co-Editors in Chief,

Karine Sénécal & Thu Minh Nguyen

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▶ EDITORIAL



Direct to Consumer Genetic Tests. An Overview of Guidelines and Position Papers

Karine Sénécal, Pascal Borry, Heidi C. Howard, Denise Avard

Abstract: A growing number of private companies are offering, via the Internet, genetic tests "directly to consumers". These types of genetic "services" raise a number of ethical concerns, in particular, the validity and clinical utility of these tests and the fact that they are conducted without a system in place to ensure that consumers understand the scope, limits and the basic meaning of the results. This GenEdit analyzes existing normative documents which address genetic tests offered directly to consumers. It identifies three broad approaches regarding the normative framework that should govern such testing. The first approach generally advocates for the ban of these services, while the second appears to allow them, provided that certain conditions are met. The third approach falls somewhere in the middle. These normative documents were also studied for specific information related to the roles and responsibilities of healthcare professionals, pre-test information, consent and communication of results, as well as the importance of educating the public and healthcare professionals. It concludes by stressing the scientific, social and moral necessity for a consistent and adapted normative framework, and the need to initiate activities for public education and public consultation.

(2009) 7:1 GenEdit, 1-14

Full Text

 LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL /  
REGIONAL

United Nations (UN) - General Assemblies: *Resolution 63/237 - Recognition of Sickle-Cell Anaemia as a Public Health Problem*

New York - December 22, 2008

Link: [URL](#)

Key Words: Access Info/Material - Beneficence - Community/Population - Education - Family - Public Health

European Society of Human Genetics (ESHG): *Genetic Testing and Common Disorders - Proposed Recommendations of the European Society of Human Genetics*  
Seville - May 18, 2009

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Cancer - Carrier Status - Commercialization - Communication of Results - Consumer - Counseling (general) - Developing Country - Discrimination - Education - Employer/Employment - Family - Genetic Screening - Genetic Testing - Insurer/Insurance - Pharmacogenomics - Privacy - Professional - Psychosocial Aspects - Research - Storage

NATIONAL

American College of Medical Genetics (ACMG): *Position Statement on Importance of Residual Newborn Screening Dried Blood Spots*

Bethesda - April 29, 2009

Link: [URL](#)

Key Words: Beneficence - Community/Population - Confidentiality - Consent - Data - DNA - Genetic Screening - Minor/Child - Newborn - Privacy - Public Health - Storage

Australia/Government - National Health and Medical Research Council (NHMRC): *Ethics and the Exchange, Sale of and Profit From Products Derived From Human Tissue: An Issues Paper - Public Consultation Draft*

Canberra - April 1, 2009

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Commercialization - Confidentiality - DNA - Equity - Research - Tissue

French National Authority for Health: *Le dépistage néonatal systématique de la mucoviscidose en France : États des lieux et perspectives après 5 ans de fonctionnement*  
St-Denis La Plaine - January 1, 2009

Link: [URL](#)

Key Words: Access Info/Material - Beneficence - Carrier Status - Consent - Genetic Screening - Newborn - Socio-Economic Aspects - Waiver of Consent

Medical Technology Association of Australia: *Inquiry Into Gene Patents*  
North Sydney - March 1, 2009

Link: [URL](#)

Key Words: Commercialization - Genetic Testing - Intellectual Property - Patents

United States - Department of Health and Human Services (DHHS) - Office for Human Research Protections (OHRP): *Guidance on the Genetic Information Nondiscrimination Act: Implications for Investigators and Institutional Review Boards*  
Rockville - March 24, 2009

Link: [URL](#)

Key Words: Discrimination - Employer/Employment - Ethical Review - Ethics Review Board - Genetic Information - Insurer/Insurance - Researcher

United States - Department of Health and Human Services (DHHS) - Office for Human Research Protections (OHRP): *Guidance on Research Involving Coded Private Information or Biological Specimens*  
Rockville - October 16, 2008

Link: [URL](#)

Key Words: Biobank - Confidentiality - Consent - Data - Patient/Participant/Individual - Privacy - Research - Tissue - Waiver of Consent

## ▶ UPCOMING EVENTS

Biobank Summer School

Organized by: The Wellcome Trust and Public Population Project in Genomics (P3G)

Date: July 1-5, 2009

Location: Hinxton, Cambridge

Information: Please visit the websites of P3G ([www.p3gconsortium.org/](http://www.p3gconsortium.org/)) or the Wellcome Trust ([www.wtconference.org.uk/](http://www.wtconference.org.uk/)) for more details.

European Summer University - Technology and Health: Law and Ethics  
Organized by: Faculté de droit de Namur

Date: July 6-8, 2009

Location: Namur, Belgium

Information: <http://www.crid.be/uee2009/home.html>, Jean Herveg, [jean.herveg@fundp.ac.be](mailto:jean.herveg@fundp.ac.be)

The Age of Personalized Medicine: 5th International DNA Sampling Conference

Organized by: Health Law Institute, University of Alberta & CRDP Université de Montréal

Date: September 16-18, 2009

Location: Banff (Alberta), Canada

Information: <http://www.genomealberta.ca/APG/>

Mapping the Genomic Era: Measurements and Meanings

Organized by: Cesagen on behalf of the ESRC Genomics Network

Date: October 7-9, 2009

Location: Cardiff, United Kingdom

Information:

Beyond the Embryo: Transnational, Transdisciplinary and Translational Perspectives on Stem Cell Research

Organized by: Brocher foundation workshop

Date: November 14-15, 2009

Location: Hermance (Lake of Geneva), Switzerland

Information: <http://www.humgen.org/conference/en/>

## ▶ TERM PUBLICATIONS

Avard D., Bucci L.M., Burgess M.M., Kaye J., Heeney C., Farmer Y., Cambon-Thomsen A., "Public Health Genomics (PHG) and Public Participation: Points to Consider", (2009) 5:1 *Journal of Public Deliberation*, 1

Abstract: Large-scale population biobanks, which aim to collect biological tissues, personal health information, and genomic data, are being introduced worldwide with the promise of increasing knowledge on chronic diseases such as diabetes and heart disease. Experts recognize the need for public participation to address the many social, legal and ethical

complexities raised by the introduction of biobanks for public health research. However many researchers and decision makers struggle with how to promote public participation. This paper presents six issues that public participation must address. These issues are then applied to three large scale genetic biobank projects: CARTaGENE, Generation Scotland, and the United Kingdom Biobank. Finally, the efforts of these biobanks will be compared to the British Columbia Biobank deliberation project, which implemented a deliberative public participation experiment on biobanking.

Avard D., Stanton-Jean M., Woodgate R.L., Pullman D., Saginur R., "Research Ethics Boards and Challenges for Public Participation", (2009) 17:2-3 *Health Law Review*, 66  
Abstract: [Not available]

Gold E.R., Knoppers B.M., "Biotechnology IP & Ethics", LexisNexis Canada Inc., 2009, 416 p.  
Abstract: [Not available]

Joly Y., "Genetic Research Tools: Recent Trends and Future Outlook", *Biotechnology IP & Ethics* (Canada: LexisNexis Canada Inc., 2009)  
Abstract: [Not available]

Knoppers B.M., "Biotechnology & Ethics", *Biotechnology IP & Ethics* (Canada: LexisNexis Canada Inc., 2009)  
Abstract: [Not available]

Knoppers B.M., "Genomics and Policymaking: From Static Models to Complex Systems?", (2009) 125 *Hum Genet*, 375  
Abstract: In the 20 years following the launching of the Human Genome Project, socio-ethical and legal responses to the policy issues raised have varied across jurisdictions. There seems, however, to be a move away from the more static, classical responses that characterized the first decade to a more epigenetic and complex one. The latter policy approach better reflects the dynamic nature of the science itself.

Knoppers B.M., "Challenges to Ethics Review in Health Research", (2009) 17:2 *Health Law Review*, 47  
Abstract: [Not available]

Silverstein T., Joly Y., Harmsen E., Knoppers B.M. for the GRID (Gene Regulators in Disease) Project, "The Commercialization of Genomic Academic Research: Conflicting Interests?", *Biotechnology IP & Ethics* (Canada: LexisNexis Canada Inc., 2009)  
Abstract: [Not available]

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